

# **Ethical Dilemmas**

## **Faced by Women as Caregivers of Frail Elders:**

### **A Qualitative Study**

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#### **Research Problem**

Women face a myriad of ongoing and complex ethical dilemmas in caring for a frail elder (Bopp & Coleson, 1996). An ethical dilemma can be defined as a conflict in which the caregiver must make a choice “between two or more relevant, but contradictory ethical directives, or when every alternative results in an undesirable outcome for one or more persons” (Loewenberg, Dolgoff & Harrington, 2000, p. 9). An example of an ethical dilemma highlights the complexity of decision making for caregivers. A spousal caregiver struggled to care for herself and also provide care for the frail elder. The frail elder was at risk for falling, had cognitive deficits and was getting out of bed at night to climb downstairs to a basement shop. The caregiver did not want to restrict the frail elder’s freedom, but after conversations with family, she decided to put a lock on their bedroom door to keep the frail elder from harming himself. The caregiver acted out of values of self-care and the care and safety of the frail elder. By putting the lock on the bedroom door, she was able to get some needed sleep, thereby taking care of herself and at the same time providing for the safety of the frail elder.

Gerontological writers have described the importance of moral dialogue involving elders, caregivers and others for the purpose of addressing caregiving ethical dilemmas on such topics as health care treatment and home care options (Bopp & Coleson, 1996; Spano & Koenig, 2003). However, rarely have research efforts examined the way caregivers personally define and make decisions about ethical dilemmas. Hence, this dissertation focused on obtaining women’s perspectives about these ethical dilemmas.

#### **Research Background, Questions and Hypotheses**

Literature about ethical decision making in caregiving contexts is mainly conceptual. Writers discuss the application of ethical principles or concepts such as autonomy, beneficence, justice and responsibility, e.g. Cole & Holstein, 1996. Few

empirically based studies explore ethical dilemmas and processes for dealing with them from the informal caregiver's viewpoint (Hasselkus, 1991; Pyke & Bengston, 1996).

Current trends in the caregiving literature continue to emphasize the ethical dilemmas and decision making processes of the professional caregiver. This is typically explored within acute care and institutional settings using bioethics models. For example, writers address professional caregivers' ethical dilemmas in dealing with end of life treatment (Cole & Holstein, 1996; Larson & Eaton, 1997) and the ethical decision making processes leading up to or occurring within institutional settings (McCullough, Wilson, Rhymes & Teasdale, 1999).

These conceptual writings on ethics and aging indicate that bioethics decision-making models address a type of decision making that is not readily transferable to long-term, home-based settings. Several factors account for this including less control of home based treatment by health care providers, the larger role of family and other informal caregivers in the decision making process, and psychosocial factors that lead to increased complexity in health care treatment, i.e. minimal financial resources.

Hence, this study focused on obtaining women's perspectives and stories about their ethical dilemmas and hard choices as well as processes or strategies they have developed for dealing with them. Most elders are cared for in their own home with only five percent of people age 65 years and older living in a structured setting on any given day (Novak, 1997). The informal caregiver's perspective becomes imperative to understanding the nature of ethical dilemmas within the home setting.

For this study, three overarching research questions were proposed to explore the ethical dilemmas and processes for dealing with them from the caregiver's point of view: (1) What are the ethical dilemmas that female caregivers face in caring for a frail elder in the home setting?; (2) What are the processes female caregivers describe in dealing with or resolving ethical dilemmas; and, (3) What recommendations do female caregivers have for enhancing services to help address ethical dilemmas?

## Methodology

This study used naturalistic inquiry to explore female caregivers' experiences of ethical dilemmas. A naturalistic paradigm adheres to assumptions about how we know and experience our world, i.e. a belief in value-explicit inquiry and multiple social constructions of reality. Furthermore, naturalistic inquiry emphasizes a qualitative design in which themes, conclusions and grounded theory emerge from analysis of the data rather than from the researcher's a priori assumptions or theories. Because minimal systematic research has been conducted on caregivers' experiences of ethical dilemmas, a qualitative design lent itself well to this exploration.

For the purpose of this study, a frail elder was defined as any person age 65 or older needing assistance with one or more activities of daily living such as bathing or ambulation. An informal, primary caregiver was defined as a woman who provides the major source of unpaid elder care. Because over seventy-three percent of the caregivers

are women, the researcher chose to interview only women for this study (NAC & AARP, 1997).

Participants were recruited from clients of a home health agency. Thirteen caregivers were selected using purposive sampling in order to obtain a broad range of perspectives concerning the research questions. A consultant panel, consisting of home health agency staff and key caregivers served by the agency, was organized by the researcher. Consultant panel members provided guidance to the researcher throughout the design process. The researcher conducted semi-structured interviews with participants, recorded field notes of observations, and conducted follow-up interviews. Individual audio taped interviews with caregivers spanned one and one-half to three hours each with follow-up interviews lasting fifteen to sixty minutes each.

The constant comparative method of qualitative data analysis as described by Lincoln and Guba (1985) was used to analyze interviews and observations. The constant comparative method involved developing tentative categories or codes for units of information. An iterative process was used to move between the raw data and tentative codes until final coding categories were developed. Specified themes and a conceptual model of the caregiver's ethical decision making processes emerged from the data analysis.

Several strategies were employed to establish trustworthiness in the study's findings. These included the use of the consultant panel, member checking and focus groups. Consultant panel members gave feedback on introductory themes and case vignettes of ethical dilemmas as a way of further refining and confirming findings. The researcher also conducted member checks as to the understanding and accuracy of findings with research participants throughout the interview process and in follow-up interviews. Finally, in focus groups, members of the consultant panel and interviewees confirmed a preliminary report of major findings.

## **Results**

Demographic characteristics such as age, ethnicity, and marital status were collected about the caregiver and frail elder. Analysis indicated that no distinct subgroups of the participants, such as adult daughters and wives, clearly distinguished the kinds of ethical dilemmas or processes for dealing with these dilemmas.

However, several major themes emerged to help form a working model of ethical decision making for caregivers (see Figure 1). Figure 1 is illustrated with an egg shaped outline. This egg is divided into two major categories. The first category (the top half of the egg) is entitled 'unique caregiving features' and includes themes about (1) the caregiving context, i.e. the home environment; (2) characteristics of the frail elder; and (3) characteristics of the caregiver, i.e. age and ethnicity, and the caregivers' perspectives or influences on the caregiving experience, i.e. the importance of spirituality.

The second category (the bottom half of the egg) includes themes about (1) values, i.e. caring and freedom; (2) ethical principles, i.e. quality of life and autonomy; (3) ethical dilemmas divided into two major areas – conflicting ethical principles such as

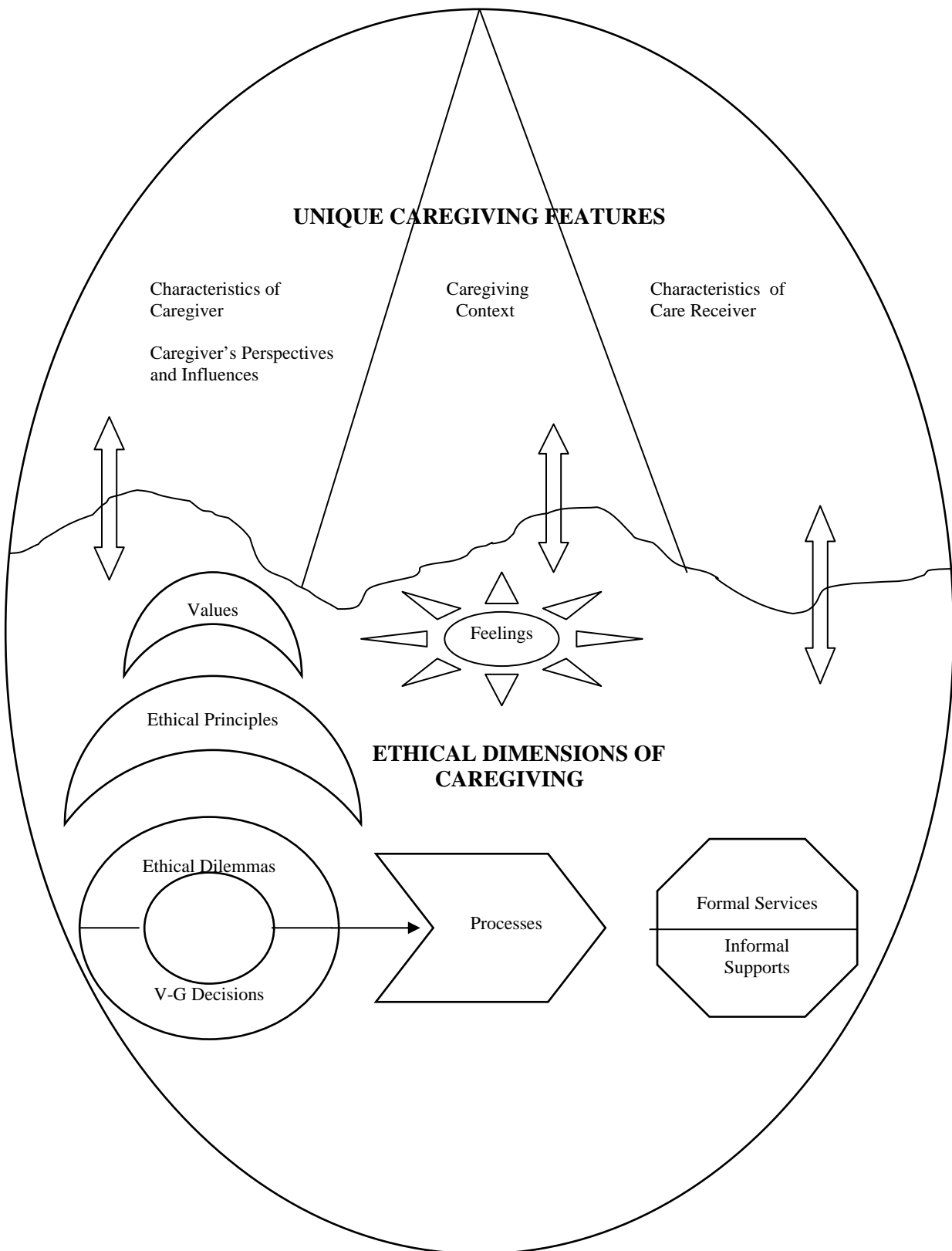
protection of life versus autonomy and topical areas such as social support; (4) value-guided decisions which are choices (not ethical dilemmas) based on guiding ethical principles and values; (5) processes for dealing with ethical dilemmas, i.e. using assertive communication or self-reflection; (6) feelings that permeate the ethical decision making process, i.e. anger, fear or guilt; and, (7) informal supports or formal services in dealing with ethical dilemmas, i.e. skilled nursing care or social support from friends.

Furthermore, the flow and connections among the various components of Figure 1 are depicted by wide arrows that point in both directions (arrows crossing on both sides of the egg's crack). The two broad categories of unique caregiving features and ethical dimensions of caregiving (the top and bottom half of the egg) interact and mutually influence one another. Other arrows or lines in Figure 1 represent only one way to diagram the interactions among the various themes. These arrows do not imply causality.

In order to illustrate the interaction among various components of the working model, what follows is a research participant's example of an ethical dilemma. The interviewee had difficulties lifting over ten pounds due to breast cancer treatment. Difficulty lifting (part of the caregiver's characteristics) contributed to feelings of fear about being able to care for the frail elder. Furthermore, the caregiver's spiritual beliefs (part of the caregiver's perspectives) helped her manage this fear. The caregiver was also afraid because she lived in a home with many stairs (part of the caregiving context), had no outside help (part of the formal services) and because the frail elder had cognitive deficits (part of the characteristics of frail elder). Furthermore, the caregiver's spiritual beliefs about staying committed to the relationship contributed to the ethical dilemma of self-care versus care for the frail elder.

The caregiver described this dilemma as involving the competing values of caring (self-care versus elder care). Caring supports respectively the competing ethical principles of protection of life for the caregiver (who has difficulties lifting) versus quality of life for the frail elder. The caregiver processed this ethical dilemma by collaborating with family (part of the informal supports) and by using assertive communication with the frail elder to insist on outside help (part of the processes for dealing with ethical dilemmas).

Figure 1. Components of ethical decision-making for female caregivers.



## Utility for Social Work Practice

All interview participants describe the ethical dilemma of putting aside personal needs such as privacy and health care treatment in order to provide care for the frail elder. The difficult balance of self-care versus care for the frail elder parallels Gilligan (1982) and others' (Skoe & Lippe, 1998) understanding of how women deal with ethical dilemmas. Putting the frail elder's care needs first has striking ramifications for social work policy and practice strategies designed to reach caregivers. It is difficult for practitioners to provide supportive services to caregivers who are participating in home health agency services or other community based programs if they do not express a need for help in facing complex and often daily ethical dilemmas. Next steps in policy and practice efforts would include finding ways to explore and assess caregivers' self-care needs while taking into account their struggle to also care for the frail elder.

Furthermore, the proposed ethical decision making model can be used in classroom and agency settings to demonstrate the complex nature of ethical decision-making that permeates the caregiving experience. Caregiving narratives of ethical decision making processes can readily illustrate mutual interactions among various components in the working model. These vignettes provide a way for social work students, educators, practitioners and administrators to closely examine the nature of caregiving and can further stimulate possible strategies for supporting caregivers.

In conclusion, female caregivers face multiple, complex and often daily ethical dilemmas as they provide home care for frail elders. The research literature has largely ignored women's distinctive voices of the ethical dimensions of caregiving. This study proposes an ethical decision making model that emerged from women's unique viewpoints about the ways in which they process and deal with ethical dilemmas as caregivers. Paying attention to the complex decision making processes expressed through women's caregiving narratives provides ample opportunities for strengthening social work's practice, policy, education and research efforts with caregivers.

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